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ABSTRACT

This study surveyed the parents/guardians of 97 youth (ages 18-24) throughout the United States who are deaf-blind and who left school in June 1996. The survey was conducted 18 months after these youth had left school. Following an introduction, this report first presents findings related to characteristics of the youth in the areas of communication, reading, mobility, health, and behavior. The next section presents data on secondary school experiences including last educational placement, related services, work experience in secondary education, and planning for transition. The section on post-school life addresses further education, support services, community involvement, living arrangements, and employment. The final two sections provide information on parental satisfaction, consider implications of the study, and offer recommendations. Among these seven recommendations are the need to provide services that promote communication development, that promote the development of literacy, that provide for education with nondisabled peers, that offer real job experience with community-based vocational training, and that provide person-centered transition planning beginning no later than age 14. (Contains 75 references.) (DB)

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ED 465 234

NTAC

Briefing Paper

National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives

Jerry G. Petroff, Ph.D.

U.S. DEPARTMENT OF EDUCATION
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Contents

Introduction 1

Characteristics of Youth who are Deaf-Blind 2
- *Communication* 3
- *Reading* 5
- *Mobility* 5
- *Health* 5
- *Behavior* 6

Past School Experience (Secondary Education) 7
- *Last Educational Placement* 8
- *Related Services* 8
- *Work Experience in Secondary Education* 9
- *Planning for Transition* 10

Post-School Life 12
- *Further Education* 12
- *Support Services* 12
- *Community Involvement* 14
- *Living Arrangements* 15
- *Employment* 16

Parental Satisfaction 18

Implications and Recommendations 18

Summary 19

References Cited 20

Introduction

Historically youth who are deaf-blind have not had the supports that are necessary for success in adult life. *The National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives* (Petroff, 1999) found that many youth who are deaf-blind have not been provided with the type or quality of education that generally yields successful outcomes in employment, independent living, and community involvement. The study revealed that upon leaving high school, these young people may expect that:

- They will not go on to participate in post-secondary education.
- They will experience high rates of unemployment and underemployment.
- They will probably not live independently.
- Their repertoire of experiences in community life will be limited.
- They will create few close relationships (other than with family members).

Of all students with disabilities, only a small number have both vision and hearing impairments. Estimates indicate that only two out of every thousand students receiving special education services are deaf-blind (Baldwin, 1993). Members of this low-incidence group are extremely diverse in their abilities, supports, and needs. These factors contribute to the difficulty of gathering reliable and detailed descriptive information, especially as it relates to post-school status. Past attempts (e.g., the National Longitudinal Transition Study) to gain an impression of the specific characteristics and status of individuals with deaf-blindness have been to no avail (Blackorby & Wagner, 1996; Wagner, 1993; Wagner, Newman, & Shaver, 1989).

The National Transition Follow-Up Study of Youth Identified as Deafblind: Parent Perspectives (Petroff, 1999) is the first research initiative to thoroughly explore the post-school life of youth who are deaf-blind. Besides gathering demographic information, the study sought information regarding the diverse characteristics of youth who are deaf-blind regarding communication, sensory status, mobility, health, and problem behaviors. It also explored secondary school experiences, especially regarding services and supports, work experience, and transition planning. Parents were asked about post-secondary experiences, education, employment, living arrangements, and community involvement. And finally, they were asked about their satisfaction with current and past services and support.

This study was designed to survey the parents/guardians of youth who are deaf-blind who left school in June 1996. The survey was conducted 18 months after these youth had left school. Their ages ranged from 18 to 24. The survey contained 86 items arranged under four general areas of inquiry: family demographics, characteristics, past school experience, and post-school life. With the assistance of the Helen Keller National Center and the National Technical Assistance Consortium of Children and Youth who are Deaf-Blind (NTAC), surveys were distributed to each of the states' federally funded deaf-blind technical assistance projects. In keeping with the guidelines for confidentiality, surveys were distributed to families by the individual state deaf-blind

projects, returned anonymously to NTAC, and then forwarded to the researcher. The state project distributed the surveys to the identified families.

The state projects reported an estimated total of 204 youth who left school in June of 1996. The number of surveys returned (102) was 44.35% of the total population and the number of surveys used in this research (97) represents 42.17% (see Table 1 for demographics).

Table 1. Demographics

Race/Ethnicity of Youth (N=97)		Type of Community (N=97)	
Native American	3%	Suburban	43%
African-American	10%	Rural	37%
Hispanic	10%	Urban	20%
Caucasian	74%		
Other	3%		

Characteristics of Youth who are Deaf-Blind

This study showed remarkable diversity in communication development, mobility, and presence of challenging behavior. One important finding was that a high percentage of youth use gestures, vocalizations, facial expressions, and/or behaviors as their primary mode of communication. The number of youth who use sign language was surprisingly low. Additionally, although the majority were nonreaders, those with literacy skills performed at a reading level of fourth grade or above.

Limitations of the Study

Although the survey method is recognized as an important and valuable tool compatible with the purposes of this study, it has certain limitations. The most fundamental limitation is the constraint of addressing complex inquiries with a limited number of survey questions. Questions need to be formulated that yield information relative to specific research questions. A finite number of items are developed to yield just enough data to adequately address each research question. Another restriction of the survey method is its inability to use results for the purposes of drawing quantitative forecasts of the future.

Despite the precautions taken in this study to ensure that the procedures conducted were reliable and the

Although these findings validate general impressions of youth who are deaf-blind, they expand upon previous literature (Baldwin, 1991; Everson, 1995; Fredericks & Baldwin, 1987; Haring & Romer, 1995; Riggio, 1992) by providing more comprehensive national data regarding the diversity. The data from this study support earlier findings, but further suggest that these individuals may not be evenly distributed across any continuum of functioning. In fact, a close analysis of the data shows that the majority of youth who are deaf-blind are divided into two very different categories: (a) youth who do not communicate with language (signed or spoken, 49.5%) and also do not walk

conclusions drawn were valid, certain limitations apply to any generalizations of findings. This study was designed and conducted to obtain the status of a specific population of young adults at a specific point in time. Therefore, no attempt should be made to generalize the results. The value of the results is reflected in the overall composite they provide of recent school leavers who are deaf-blind. In addition, impressions about the diversity of the entire population are articulated, which may or may not reflect the characteristics of any one individual.

Lastly, the interpretation of the results of this study must be viewed in its appropriate context. This research was conducted from the perspectives of parents who are a reliable source of the kind of information sought by this study. However, their responses are based on judgments, recollections, and perceptions. Their views are naturally influenced by their emotional and psychological involvement with their children.

independently (44%), and (b) youth who communicate primarily using spoken and/or sign language 49.5% and also walk independently (56%). This sharp distinction between two majority groups within this population has not been clearly reported in the past. An analysis of the data regarding communicative function, reading ability, and mobility results in a profile of these two majority constituencies that may require two very different kinds of educational and post-educational experiences and support.

Communication

Although a few authors suggest that individuals who are deaf-blind communicate in a variety of ways (Welch & Huebner, 1995), there has been no indication of the extent to which they communicate using nonsymbolic methods. There does appear to be an impression that those individuals who are deaf-blind and have additional disabilities that would affect the development of language are only "one small segment of people who are deaf-blind" (Collins, 1993, p.141). The findings of this study suggest that fully one half of the youth do not use symbolic communication (see Table 2). This may be explained as either (a) the concomitant effects of multiple disabilities preventing the development of language or (b) language-based communication systems have not been taught or have not been made available to these youth (Gothelf & Brown, 1996). The survey was designed with the assumption that all youth demonstrate some form of communication; therefore, parents were not given the opportunity to respond that their children did not have any method of communication at all.

Table 2. Primary Method of Communication

Communication Method	N=97	Number of Expressive Words		
		150+	50-100	<50
Nonsymbolic	50%			
Speech (symbolic)	32%	72.5%	7.5%	20%
Sign Language (symbolic)	18%	35%	28%	37%

The wide range of communicative functioning of individuals who are deaf-blind to include the use of spoken language has been documented (Rowland, 1987; Rowland, Schweigert, & Stremel, 1992; Stremel, 1991; Stremel & Schutz, 1995). However, indications of the frequency of speech usage did not approach those of this study. Issues of communication for individuals who are deaf-blind focus on either early communication training (Huebner, Prickett, Welch & Joffee, 1995; Rowland, Schweigert & Stremel, 1992; Stremel, 1991; Van Dijk, 1967) or augmentative communication systems (Rowland, 1987; Strong et al., 1993). Despite the number of youth who use speech as a primary form of communication, a review of current literature shows very little information, research, and emphasis on the promotion/training of speech skills for youth who are deaf-blind.

The data from this study suggest that sign language may be used most often in conjunction with other modes of communication, serving as an augmentative rather than primary system (Table 3). Individuals who are considered culturally deaf (Collins, 1995) and have no additional disabilities are likely to be included as the 18% of those who use sign language as a primary mode of communication.

Table 3. Modes of Communication

Types of Communication	Expressive (All that apply)	Receptive (All that apply)	Primary (One)
Spoken language	36.1%	69.1%	31.6%
Sign language (visual)	27.8%	29.9%	16.8%
Sign language (tactile)	09.3%	12.4%	01.1%
Gestures, vocalizations, etc.	68.0%	56.7%	49.5%
Electronic picture/symbol system	05.2%	03.1%	01.1%
Writing/Braille	12.4%	09.3%	0
Pictures/objects	13.4%	15.5%	0
Valid cases	97	97	95

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Reading

In an attempt to gain insight into the academic abilities of youth who are deaf-blind, the respondents were asked to describe their child's reading ability. Once again the population seemed to be divided between two very different subgroups (Table 4). Little or no information has been previously published regarding reading and academic abilities in deaf-blind youth.

Table 4. Reading Ability (N=94)

Nonreaders	62%
Reading above a 4th grade level	27%

Mobility

The results of this study regarding mobility further demonstrate that a large subgroup of youth who are deaf-blind have additional disabilities. Campbell (1995) states that these youth are more likely to have motor impairment as a result of central nervous system dysfunction than as an artifact of their sensory impairment. These data suggest that other motor involvement may negatively affect the youths' ability to utilize language systems based on speech and/or sign.

Table 5. Mobility (N=94)

Walks independently	56%
Not independently mobile	43%
Uses wheelchair but is independently mobile	1%

Health

In order to expand the understanding of the diversity of this low-incidence population, the study obtained descriptive information regarding health and adaptive behavior. The vast majority of youth were reported to have fair to excellent health (see Table 6). There is no indication that individuals who are deaf-blind will have significant health care needs. However, it has been reported that when visual and auditory impairments are related to central nervous system damage, medical problems may also be present (Campbell, 1995). Many causes of deaf-blindness include associated medical and health concerns (Boys' Town National Research Hospital, 1990; O'Donnell, 1991; Wolf-Schein, 1989). The results of this study indicate that if medical problems are present, the majority are being managed effectively (Table 7 and Table 8). This study focused on individuals in the late teenage years; it may be that health problems are more of an issue in early childhood.

Table 6. General Health (N=94)

Fair	59%
Excellent	36%
Poor	5%

Table 7. Medication (N=95)

Purpose of Medication	Percent
Mood, anxiety, sleep, or behavior	34%
Seizure control	57%
Other health-related problem	55%
Total	73%

Table 8. (N=93)

Seizure Activity	Percent
Weekly/or more often	15%
Monthly	5%
Less than monthly	9%
Total	29%

Behavior

Many individuals who are deaf-blind engage in problematic or challenging behaviors which often begin early in life (Mar, 1992). Since there is a recognized correlation between behavior and communication (Carr & Durand, 1985; Durand, 1990), it is not surprising that individuals who are deaf-blind present difficulties in this area (Crimmins et al., 1995). Over half of the respondents reported that their children engaged sometimes or frequently in unusual or repetitive habits (Table 9). This is not remarkable since the absence of or diminished sensory functioning increases the need for stimulation and often results in the development of self-stimulatory behavior (Choss & Fernandez, 1980; Haring & Romer, 1995). Socially offensive behavior is reported as the next most frequent type of behavior. This is not surprising. The development of appropriate social behavior is often learned through the distance senses by modeling the behavior of others. The majority of respondents indicated that their child sometimes engaged in hurtful self-injurious, aggressive, or destructive behavior.

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Table 9. Behavior (N=95)

Behavior	Percent
Unusual or repetitive habits	39%
Socially offensive behavior	38%
Hurtful to self	35%
Hurtful to others	27%
Destructive to property	19%

Given that problematic behavior among students who are deaf-blind has been reported previously (Crimmins et. al., 1995; Everson, 1995; Frey, 1988; Gothelf, Rikhye & Silberman, 1988; Goetz, 1993; Haring & Romer, 1996) and the known link between communication and the incidence of challenging behavior, it was surprising that reported levels were not higher.

Past School Experience (Secondary Education)

With the exception of deaf-blindness, data exist for nearly all disabilities regarding the nature of a young adult's exit from school (Wagner, 1993). The present study shows that youth who are deaf-blind seem to depart from the pattern of students with other disabilities in regards to the manner in which they left school (Table 10). Students with deaf-blindness are more likely to remain in school through age 20.

Table 10. Comparison of Manner of Leaving School

	Youth w/deaf-blindness (N=97)	Youth w/disabilities[1]
Age out	50%	8%
Graduate w/diploma	47%	59%
Drop out	3%	33%

The data show that students who are deaf-blind, regardless of need, remain in school until they no longer are entitled to a public education. One would expect that completion of a free and appropriate public education should be linked to successful adult outcomes. Given that students who are deaf-blind are more likely to remain in school until the maximum age, one would expect successful outcomes in employment, independent functioning, and community integration. The results of this study do not support these expectations.

1 *NLTS (National Longitudinal Transition Study, 1996)*

Last Educational Placement

Students who are deaf-blind are currently educated in a variety of settings across a continuum from least to most restrictive environments (Baldwin, 1992). The findings of this study corroborate this impression while providing further detail about the nature of educational placements (Table 11).

Table 11. Secondary Educational Placement (N=93)

Segregated special education		82%
Special education/Self-contained in gen. ed.	26%	
Special education/Separate school	28%	
Special vocational education/Separate school	11%	
Other	17%	
General education settings		18%

With an increasing emphasis on the importance and benefits of educating all students in inclusive regular educational settings (Ford & Fredericks, 1995; Stainback & Stainback, 1995; Villa & Thousand, 1992), these results are noteworthy. It appears that students who are deaf-blind are among those who continue to be segregated despite legal mandates, research, and practices that support inclusion within our schools and communities. The continued separation of this group during school will only lead to their continued separation and isolation in adult life. However, the 18% of youth educated in regular education settings shows a favorable increase from the past

Related Services

It is often assumed that students who are deaf-blind require an elevated number of related services to address their specialized educational needs (Huebner et al., 1995; Reiman & Johnson, 1993). In the absence of prior existing data, the results of this study describe and quantify this issue. From a list of 15 related services frequently used by students with disabilities, respondents were asked to identify all the services their child received during his/her last year of school (Table 12).

Communication. Sixty percent of the youth received speech and language services. This appears remarkably low for this population. The significant impact of hearing and vision loss on the development of language and communication would appear to necessitate support in this area throughout a student's educational career regardless of the level of functioning (Prickett, 1995; Rowland, 1987; Stremel, 1991). Communication is central to the education of students who are deaf-blind (Ford & Fredericks, 1995; Stremel & Schutz, 1995).

Orientation and Mobility. Considering that approximately 50% of the youth ambulate on their own (Table 5) and have significant enough sensory impairment to be considered deaf-blind, one would think that the rate of orientation and mobility services should be even higher (see Table 12, f). The low level of orientation and mobility services may be due to the fact that educational programs do not routinely provide this type of support to

students with severe disabilities (Gee, Harrell, & Rosenburg, 1987), despite the necessity of effective orientation and mobility skills for optimal independence.

Support. Twenty-five percent had a single dedicated support person with them at all times. It is striking that 80% of the students are in segregated programs, yet 25% still required and had the benefit of one-to-one support.

Table 12. Related Services/Final School Year (N=97)

a. Speech and language therapy services	60%
b. Physical therapy	45%
c. Vision education services/Teacher of the blind/vi	42%
d. Occupational therapy services	41%
e. Hearing education services/Teacher of the deaf	32%
f. Orientation and mobility training	31%
g. Audiological services	30%
h. Social work services/Support	29%
i. Vocational rehabilitation services/Consult	29%
j. Intervener/1 to 1 teacher's aide	25%
k. Job coach support	21%
l. Personal care attendant	20%
m. Nursing services	17%
n. Sign language interpreter	17%
o. Personal counseling or therapy	8%

Work Experience in Secondary Education

The positive influence of secondary educational work experiences for students with disabilities is well documented (Cobb & Neubert, 1992; Johnson & Rusch, 1993; McDonnell, Ferguson, & Mathot-Buckner, 1992; Wehman & Hill, 1980; Wehman, 1981; Wehman, Kregel, & Barcus, 1985). If the goal of education is to prepare students to achieve optimal independence and to function as contributing members of their communities, then it seems logical to provide an education rich with real-life work experiences. Best practice in secondary education indicates that students with disabilities, including those with deaf-blindness, must have real work experiences (Everson, 1995; Falvey, 1986; Nisbet, 1992). This training should begin during the student's primary education and be systematically expanded (Brown et al., 1979; Nisbet, 1992; Wehman, 1985).

An extremely low percentage of youth were found to have had an opportunity for vocational instruction and real work experience in the community (Table 13). It is difficult to expect that a student who is deaf-blind will function independently and productively in adult life without prior instruction in real-life settings when so many (32%) are not provided with relevant community working experiences. Students who are successful in obtaining and maintaining paid work in community settings following high school are those who received ongoing opportunities for training in community employment sites throughout their high school careers and who obtained paid employment before graduation (McDonnel et al., 1992).

Table 13. Vocationally Oriented Program/Work Experiences (N=93)

Not in a vocational program	32%
Classroom setting (simulated work experiences)	20%
Community-based instruction	12%
Competitive/Supported employment experiences	8%
Sheltered employment experiences	5%

Apparently real work for real pay is not being considered as a possible outcome for the majority of youth who are deaf-blind. Most are either not in vocational programs or are participating only in classroom activities or sheltered employment settings. Only 8% of the youth were reported as having competitive or supported employment experiences as a component of their secondary education. Even adding those youth reported as having community-based instructional experiences, the number of youth remains well under one quarter of those surveyed.

Planning for Transition

In 1990, amendments to the Individual with Disabilities Education Act mandated that schools address transition from school to adult life within the student's Individual Education Plan (IEP) starting at age 16. Depending upon whether the student is graduating with his or her nondisabled peers, transition planning should occur from 2 to 5 years prior to leaving school. This present study indicates that the vast majority of youth who are deaf-blind leave school at the maximum age of 21 (Table 14). Therefore, for most students who are deaf-blind, transition planning would be expected to occur for at least 5 years. A minimum of 4 years of formal transition planning is needed to realize successful outcomes for student with disabilities (Halpern, 1993; O'Leary, 1992; Romer & Romer, 1995; Wehman, Moon, Everson, Wood, & Barcus, 1987; Wehman, Moon, & McCarthy, 1987).

Table 14. Transition Planning (N=95)

No written transition plan	40%
Engaged in transition planning < 1 year prior to graduation	33%
Never engaged in formal transition planning	23%
Engaged in transition planning - 2 years	23%

Despite mandates in federal regulations, the majority of students in this study did not receive adequate transition planning. These results raise serious concerns regarding current educational practices for youth who are deaf-blind since there is a strong correlation between comprehensive, longitudinal transition planning and successful transition to adult life (O'Leary, 1992; Wehman et al., 1985).

Best Practices in Transition Planning. Planning for the future for a student with a disability is a complex process in which traditional educational planning vehicles often are not sufficient (Mount & Zwernik, 1988; Nisbet & Hagner, 1987; O'Brien, 1987). Transition planning must include methods that focus on the students' and their families' visions of the future and do not rely solely on the judgment of professionals. A minority of students in this study participated in these types of activities (Table 15).

Interests and Preferences. Identification of the interests and preferences of students and their parents is a crucial part of the transition planning process (Mount, 1992; O'Brien, 1987). It is difficult to develop a plan for any student's future without authentic input from the individual and his or her family. Only 40% of the students' and/or parents' interests and preferences were identified as a component of the transition-planning process (Table 15).

Table 15. Activities that Occurred in the Transition-Planning Process (N=97)

Discussion at IEP meetings	78%
Additional planning meetings	40%
Identified students' interest/preferences	40%
Identified Parents' interest/preferences	40%
Parent training in transition	18%
Person-centered planning	12%
Local/Community team task forces	10%

Person-Centered Planning. Person-centered planning refers to the use of a process tool to gather information and clarify a path for an individual's future by documenting relevant background, experiences, preferences, current life situation, and other important variables (Forest & Pearpoint, 1990). Person-centered planning departs from developing a plan for an individual that is rooted in what the system can or is willing to provide (Mount, 1992). Only 12% of youth and their families in this study were involved

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in person-centered planning. Findings of this study show a dramatic need for high quality transition planning based on a person-centered approach that yields relevant individual outcomes.

Post-School Life

Further Education

There are increasing opportunities for youth with disabilities to pursue education after high school (Blackorby & Wagner, 1996; Chadsey-Rusch & O'Reilly, 1992). These opportunities include regular and special programs within 4-year colleges, community colleges, technical schools, and a variety of vocational rehabilitation programs (Table 16). Seventeen percent of the youth in this study attended post-secondary educational programs within 2 years of exiting from high school. None attended a 4-year college.

Table 16. Post-Secondary Education (N=93)

Attended a vocational rehabilitation program	8
Attended community college	5
Attended a vocational/technical school	2
Attended adult school	1
Attended a 4-year college	0

This study asked the parents of those youth who were not currently participating in a post-secondary program, if they had any plans for the youth to attend a program within the next year. Of the 14% affirmed plans for attending a post-secondary program, the majority indicated that they expected their child to attend a vocational rehabilitation program. This suggests that these individuals were waiting for a placement in an vocational rehabilitation program such as the Helen Keller National Center, Sands Point, New York.

Support Services

It is widely recognized that individuals with deaf-blindness require a variety of ongoing support services to gain access to and maximize their participation in the community (Everson, 1995; Reiman & Johnson, 1992; Watson & Taft-Watson, 1993). The majority of young adults who are deaf-blind are not provided with the types of adult support services necessary to achieve optimal independence and quality of life (Perreault, 1993; Watson & Taft-Watson, 1993).

This study attempted to describe the types of adult services being provided for young adults who are deaf-blind (Table 17). Although the results were varied, some overall conclusions can be drawn about the total population.

Service Coordination. Coordination of the various services is important for children who are deaf-blind (Everson, Burwell, & Killam, 1995; Frey, 1988). The majority of

respondents reported that service coordination was needed and was being provided (Table 17, c). The complexity of the effects of deaf-blindness, combined with a lack of trained deaf-blind specialists, often results in the provision of an elevated number of services (Best, 1992; Riggio, 1993) to support the educational and adult needs of these individuals. To substitute for the support of one professional specializing in deaf-blindness, an array of support services are provided.

Community Involvement. These findings corroborate the overall impressions previously reported regarding the level and quality of community involvement of youth who are deaf-blind (Table 17, a,g,k). Direct intervention and appropriate support may be required for individuals who are deaf-blind so they may access the community and its members.

Communication and Language. The identified need for continued communication and language services (Table 17, m) may indicate that many youth are leaving school without formal communication systems and skills. It may, however, also reflect the fact that communication and language abilities continue to develop throughout life. According to this survey, these services are inadequate. Their lack may adversely affect the ability of deaf-blind youth to pursue a successful adult life.

Transportation. Lack of transportation often prevents an individual with a disability, specifically deaf-blindness, from engaging in employment or accessing community services (Everson, 1995; Haring & Lovett, 1990; Hasazi, Gordon, & Roe, 1985). Only one-fifth of the respondents identified transportation as a support service that is needed but not provided (Table 17, d,f). However, it should be noted that if these youth don't have jobs or places to go, then transportation is not an issue.

Table 17. Needed Support Services (N=97)

Support Services	Provided and Needed	Provided and Not Needed	Not Provided and Needed
a. Income assistance	83%	2%	8%
b. Medical/Dental services	74%	3%	11%
c. Service coordination	73%	6%	9%
d. Transportation/Daily	63%	2%	20%
e. Med. equip., supplies, medicines	58%	3%	12%
f. Transportation/Non daily	48%	2%	27%
g. Personal assistance services	48%	2%	20%
h. Adaptive equip/Assistive devices	39%	6%	26%
i. Residential support	37%	4%	24%
j. Physical therapy	36%	2%	24%

k. Rec./Leisure support services	33%	6%	39%
l. Occupational therapy	31%	5%	21%
m. Communication & lang service	27%	5%	36%
n. Employment services	27%	4%	25%
o. Respite care for caregivers	26%	8%	26%
p. Vision services/Support	23%	5%	26%
q. Vocational/Technical education	20%	1%	28%
r. Orientation & mobility services	19%	8%	20%
s. Mental health or counseling	15%	12%	16%
t. Food assistance/Stamps	15%	5%	19%
u. Sign language interpreting	14%	5%	17%
v. Self help/Support groups	10%	6%	30%
w. Adult literacy/Education	2%	8%	17%

Community Involvement

Deaf-blindness severely limits an individual's contact with people and things in the environment. This isolation often impedes his or her ability and opportunity to participate in community activities (Haring & Romer, 1995). Isolation, compounded with difficulties in communicating with others, puts individuals who are deaf-blind in jeopardy of not developing a social support network (Gee, 1994; Haring & Romer, 1996). The lack of a support network may further result in limited access to community activities.

In order to gain insight into the current involvement of youth who are deaf-blind in community/recreational activities, parents were asked to indicate which of 16 listed activities their child participated in routinely or at least twice a month. Most do not routinely engage in a wide variety of activities (Table 18). Their responses raise concern about the extent to which participation in community activities is limited for deaf-blind youth. Activities receiving fairly high response rates (50%-60%) included shopping/banking, going for a walk or to a park, going out to eat, and attending a religious service.

In response to the question, "Does your child have friends other than family members or paid people (service providers)?" nearly 50% of the youth were reported as having no friends other than family members or paid people. This fact, plus lack of participation in community activities, was one of the most dramatic results of this study. These young adults are isolated not only by the nature of their disabilities but also because they lack friends or a social life outside of the family.

Table 18. Community Involvement (Engaged at least 2 times per month) (N=97)

a. Shopping/Banking	60%
b. Going for a walk or to a park	60%
c. Going out to eat	57 %
d. Attending a religious service	41%
e. Visiting a friend	38%
f. Enjoys outdoor activities (e.g., hiking)	26%
g. Going to the movies, concert, or play	25%
h. Going to a meeting of a club or organization	20%
i. Going to the library	18%
j. Going to a sporting event	13%
k. Participating in Special Olympics	13%
l. Going on date or to a party	12%
m. Participating in individual sports	10%
n. Using the Internet/e-mail	7%
o. Participating in team sports	6%
p. Taking adult classes (fitness, art, etc.)	4%

These results regarding community involvement address issues that go far beyond programs, placements, and support services. In addition to having an individual job and home, access to the community for recreation and leisure is essential for all members of our society. Access to friends and activities can be the vehicle that allows "travel from loneliness and isolation to socialization and a richer life" (Bettica, 1976, p.7).

Living Arrangements

Housing opportunities for people with disabilities have changed from the traditional sheltered, segregated options toward a wide array of alternatives within the community (Racino, Walker, O'Connor, & Taylor, 1993). This study asked parents to report their child's current living arrangement (Table 19) as well as where they would like their children to live within the next several years. Currently, well over half of the youth live at home with their family.

Table 19. Living Arrangements (N=95)

At home with family		61%
Residential Care Environment		34%
Supportive living arrangement	15.8%	
Foster home	1.0%	
Nursing home	2.1%	
Residential college/Training program	2.1%	
Public institution	3.2%	
Private institution	5.3%	
Other	4.2%	
Living independently		5%

One of the most significant findings regarding living arrangements was that one-third of the parents would like their child to move to a supportive living arrangement within the next several years. The most disconcerting result was that over 10% of the youth are living in either public/private residential institutions or nursing homes.

Employment

Individuals with disabilities are often reported to have high rates of unemployment. This study found an unemployment rate of over 80% among this group of youth who are deaf-blind (Table 20). Only two of the youth were working full time and only three were competitively employed. Since the national unemployment rate at the time of the study was well under 5% for the general population, this extremely high rate of unemployment for these youth who are deaf-blind is problematic.

Table 20. Employment Statistics (N=94)

Unemployed	82%
Working for pay	18%
Working full-time	2 youth
Working part-time	13 youth

This dim picture of the employment status of youth who are deaf-blind may be explained by considering the reasons provided by the parents/caregivers for the youth's unemployment or underemployment (Table 21). Although no parent said they did not want their child to work, more than one third indicated that they did not think their child was capable of work (Table 21, a). If parents see their adult children as incapable, the young people will have little opportunity to demonstrate their capacity for work (Bryen, Newman, Reiter, & Hakim, 1987).

Table 21. Reasons for Unemployment or Underemployment (N=97)

a. I don't think my child is capable	34%
b. Lack of/underdeveloped job skills	27%
c. Lack of jobs in the area	25%
d. Lack of ongoing supports	20%
e. Lack of job training programs	18%
f. No one to help fund a job	12%
g. Lack of initiative/doesn't appear to want to work	11%
h. Not able to work because of health	10%
i. Waiting list for supported work	10%
j. No transportation available	9%
k. Don't want wages to impact on SSI benefits	7%
l. Waiting list for sheltered workshop	7%
m. I don't want him/her to work	0%

Over the past decade, there has been an increasing emphasis on providing services to support individuals with the most severe disabilities to participate in employment and other aspects of independent adult life (Johnson, Bloomberg, McGrew, Price, & Lin, 1992; Johnson, McGrew, Bloomberg, Lin, & Bruininks, 1995). There is growing evidence that all adults who are deaf-blind can work, provided the appropriate supports are in place (Everson, 1995). The results of this study in which parents report a lack of jobs (Table 21, b) and employment supports (Table 21, d), indicate that these youth require support to engage in employment. The exclusion of youth who are deaf-blind from the workforce appears to have less to do with type or severity of disability than with programmatic and personnel barriers in supported employment (Everson, Burwell, & Killam, 1995).

An additional notable result of this present study was that over one quarter of the parents reported that their children lacked or had underdeveloped job skills (Table 21, b). These results are compatible with the secondary school experiences of these youth. Their secondary school experiences did not reflect educational practices that are recognized to promote employment: community-based instruction, job sampling, cooperative education, and developing direct work related skills. Although it may not be the only factor that explains this extremely high rate of unemployment, there is every indication that appropriate application of transition-sensitive best practices in secondary education may be a major factor affecting post-school success.

Parental Satisfaction

The primary purposes of this study were to describe the diversity among a representative group of young adults identified as deaf-blind, their secondary education experiences, and their current post-school life. The data relating to secondary education experiences and current post-school life raise serious concerns. The secondary educational practices known to promote successful transition to adult life have not been consistently implemented. In addition, there are extremely high levels of unemployment, the vast majority of youth are not living independently, and the majority are socially isolated. One might expect that parents would report low levels of satisfaction regarding their children's circumstances, but this was not the case. Within every category the majority of parents reported that they were either very or somewhat satisfied with the past school services and/or the current post-school life of their child.

The highest levels of satisfaction were reported in consideration of the current post-school life of the youth. Nearly all of the parents reported that they were very or somewhat satisfied with the current living situation of their child. Considering that the majority of youth live with their families it may be concluded that independent or semi-independent living is not a high priority for the parents of those who have recently left school.

Implications and Recommendations

The results of this study lead to a series of recommendations for educational programming and support for students who are deaf-blind. It is intended that these recommendations assist both school personnel and parents as they develop and implement educational programs that promote a successful transition from school to adult life.

1. Nearly one half of the youth left school without any formal communication system. Educational programs must provide services that promote communication development in students who are deaf-blind. These must include strategies for augmentative and alternative communication.

2. Problematic and/or challenging behavior may affect an individual's ability to gain employment, engage in meaningful community activities, and have relationships. Approximately one-third of the youth involved in this study sometimes or frequently exhibited problematic behavior.

3. High levels of illiteracy and a need for post-school education to promote the development of literacy were reported. Public and adult educational programs must address this need and provide direct instruction to promote literacy in students who are deaf-blind.

4. The vast majority of students who are deaf-blind are educated in highly segregated settings. The current best practice in special education focuses on the benefits of heterogeneous education. Students who are deaf-blind should be provided with the opportunity to be educated with their hearing, sighted, and nondisabled peers.

5. The majority of youth did not receive employment services or community-based vocational training. Youth who are deaf-blind should be provided with the benefit of real job experiences and community-based vocational training within their public school career. This is especially important considering the evidence that gaining post-school employment is influenced by experience within secondary education for all students with disabilities.

6. Since transition planning is legally mandated as well as recognized as essential for achieving post-school success, it must occur for all youth who are deaf-blind. Furthermore, transition planning must reflect a person-centered approach. It should begin no later than age 14 and continue until the child leaves school. The student and family must be active and equal partners in this process.

7. Individuals who are deaf-blind are a highly diverse group of people, each with individual, specialized needs. School personnel and parents should develop and implement systems of educational support and training that are geared to the unique abilities and needs of each youth. Some students who are deaf-blind may need the expertise of individuals who understand the concomitant effects of both sensory and cognitive impairment, whereas others require the expertise of individuals who understand the impact of vision and hearing loss upon students who do not have any additional disabilities.

Summary

The past school experience of the youth included in this study showed an overwhelming tendency for these individuals to be educated in segregated educational settings such as separate schools and classrooms. Within these settings, it was affirmed that the youth were provided with a large number of related educational services such as speech and language therapy, occupational therapy, and physical therapy. In addition, the results showed at least one third of the youth were not engaged in any vocational programs and that only a few of the youth were involved in real work experience. Finally, the results, which indicated the absence of and/or poorly engaged transition planning, may have important implications.

The study shows that a large majority of youth who are deaf-blind are not working or are underemployed. They are living primarily with their parents with little hope for independent living in the near future and have a narrow span of participation in community activities. The most remarkable of these results show that half of these youth have few friends outside their families and/or people who are paid to be with them. Additionally, over 50% of these youths are living at home with their parents and a majority of these parents want them to remain living at home. These results strongly suggest that we need to implement additional ways to support youth and their families during their years in school as well as those years that follow.

The overall recommendations from this study may be articulated under two major areas. First, the unique needs of individuals who are deaf-blind must be recognized and addressed through the provision of specialized services and support—specifically, appropriate transition planning and associated effective educational practices. This

includes the recognition that individuals who are deaf-blind need and have a right to communicate. No student should leave school without some formal and effective communication system. The provision of appropriate specialized services appears to be the key to ensuring that these individuals do not lead a life of isolation and nonproductivity. Second, those responsible for the provision of education and support to individuals who are deaf-blind need to develop ongoing protocols to assess the effectiveness of their efforts and ensure that these individuals are being provided with appropriate support and services. Parents and individuals themselves must be included in the development of services and the ongoing evaluation of effectiveness. One of the most striking results of the current study was that 80% of youths were not working for pay. It is clear that outcomes for youth who are deaf-blind must be dramatically improved. This can only be accomplished by monitoring the outcomes of youth and adjusting educational support as needed.

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